Parkinson's Foundation

Parkinson.org

Processing a Challenging Hospital Experience: Providing a Tool for People with Parkinson's to Document a Difficult Stay and Determine Next Steps

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Introduction

For people with Parkinson's disease (PD) and their loved ones, a planned or unplanned visit to the hospital can be stressful. People with PD are at greater risk for experiencing challenges in the hospital related to medication and mobility issues. This can often result in complications such as worsening symptoms and lead to increased lengths of stay. After a difficult hospital stay, many people are unsure of what next steps to take, if any.

By documenting what happened, people with PD can more effectively:

- ✓ Process a difficult experience
- ✓ Determine next steps
- ✓ Request resources and support from the Parkinson's Foundation

Methodology

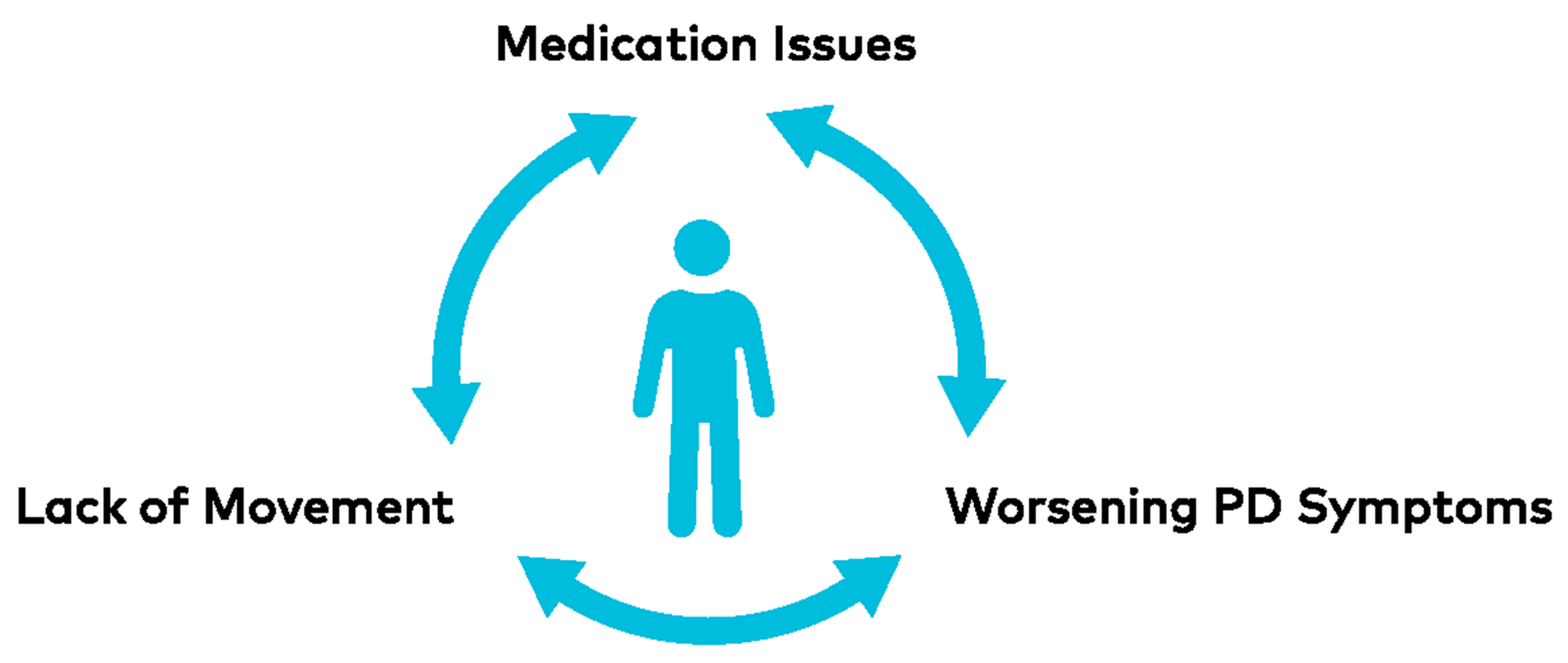
To create this community-facing resource, the Parkinson's Foundation collaborated with its People with Parkinson's Advisory Council, other members of the PD community, the Foundation's chapter field staff, and an interdisciplinary team of PD clinicians who all provided review and feedback.

The final product is a questionnaire, formatted as a digital form and accessible on the Foundation's website. The resource guides users through a series of robust, PD-relevant questions about their hospital stay and provides suggestions for receiving support and preventing future harm.

PD in the Hospital and "The Symptom Spiral"

Already a delicate balance, PD symptom management can be even trickier in the hospital. **"The Symptom Spiral"** can be a debilitating cycle that puts you at risk for falls, swallowing changes, muscle deterioration, medication side effects, mental and physical decline or decreased independence.

We call this cascade of new challenges "the Symptom Spiral," shown below.



Results

In March 2026, the Processing a Challenging Hospital Experience resource was prominently featured in national promotion materials for Patient Safety Awareness Week, an annual event designed to highlight the importance of patient safety and engagement of patients, families, and healthcare professionals in promoting safer care. This included social media posts, email blasts, and hospital safety webinars for professionals and community members.

Conclusion

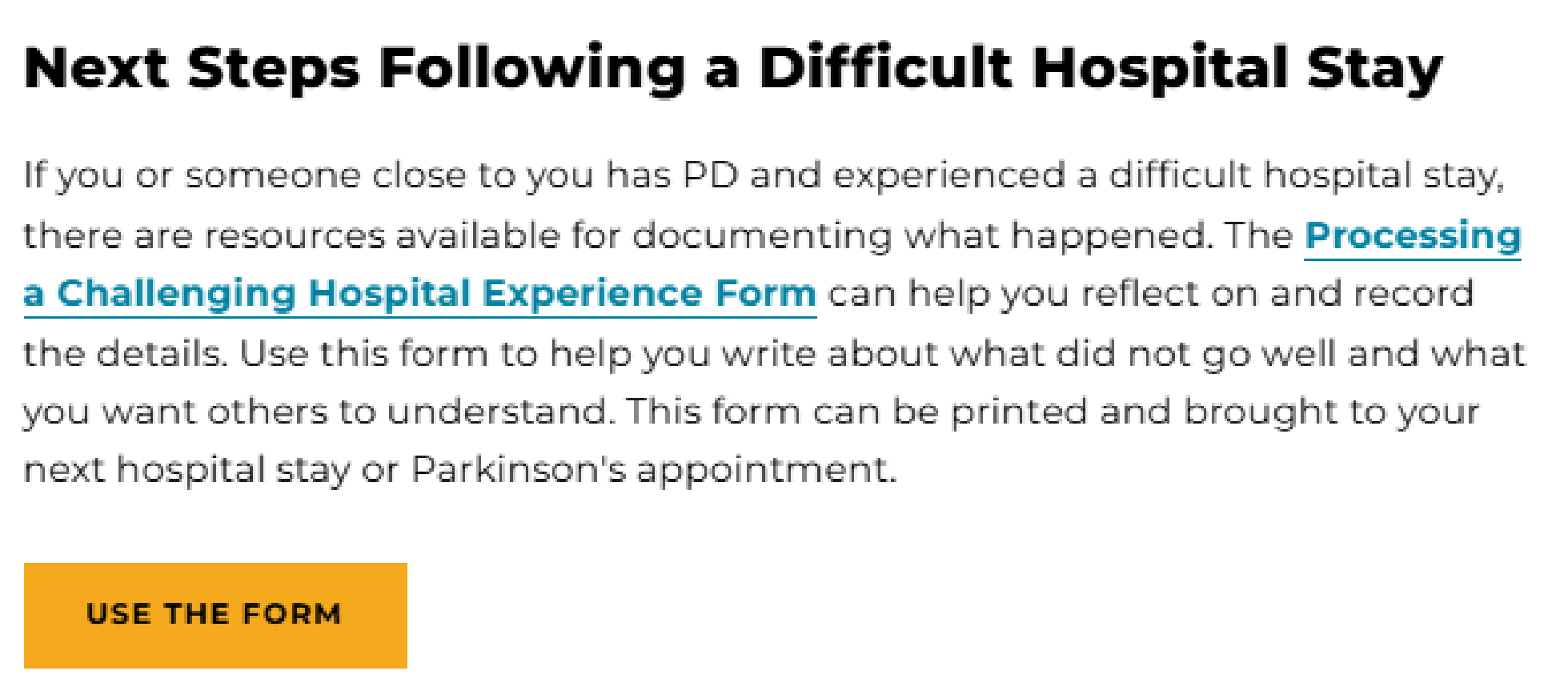
People with PD and their care partners have the option to submit their answers anonymously, share their experiences with the PD community to help raise awareness, and/or request outreach and resources from the Parkinson's Foundation.

Forms can also be downloaded as a PDF, saved, and printed to share back with the hospital or for reference during a future PD appointment or hospital stay.

To date, the Foundation has received submissions from people with PD and their care partners in:

- **11** states representing
- **10** of the Foundation's **18** US-based chapters

Processing a Challenging Hospital Experience form, available on Parkinson.org/HospitalSafety:



Next Steps Following a Difficult Hospital Stay

If you or someone close to you has PD and experienced a difficult hospital stay, there are resources available for documenting what happened. The **Processing a Challenging Hospital Experience Form** can help you reflect on and record the details. Use this form to help you write about what did not go well and what you want others to understand. This form can be printed and brought to your next hospital stay or Parkinson's appointment.

Or scan this QR code with your phone camera to go to the Processing a Challenging Hospital Experience Form

Parkinson's Foundation

Processing a Challenging Hospital Experience

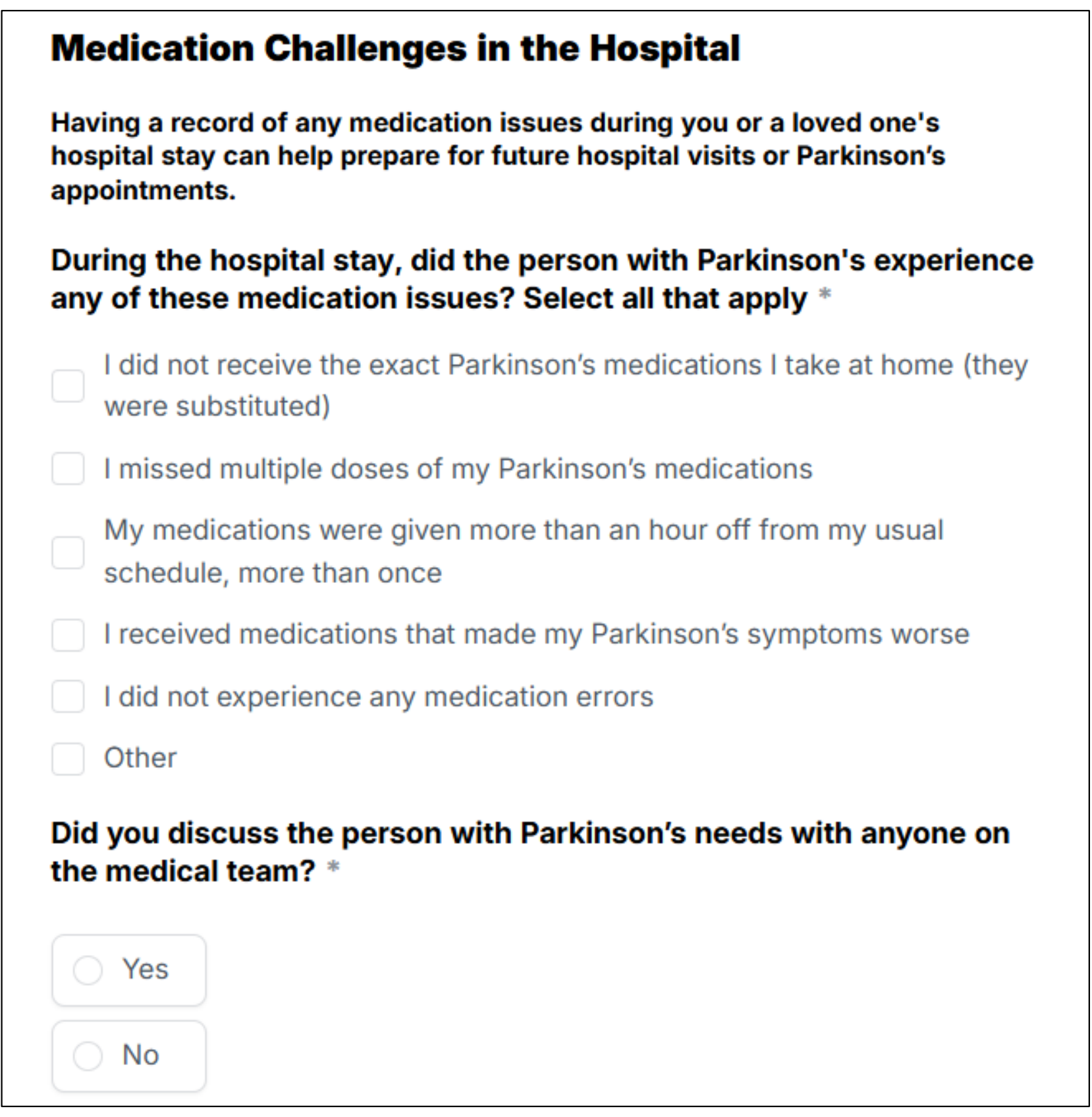
If you or someone close to you has Parkinson's disease (PD) and experienced a difficult hospital stay, this form can help you reflect on and record what happened. Use this form to help you write about what did not go well and what you want others to understand.

Sharing your hospital story can help improve care for people with PD, but participating is entirely your choice. We will not save your name or contact information unless you give the Parkinson's Foundation permission at the end of this form. After submitting, you will have the option to download, save and print your responses for future reference. You may wish to bring a printed copy to your next hospital stay or Parkinson's appointment.

Your Hospitalization Details

Are you a person with Parkinson's, a care partner or a family member? *

○ Person with Parkinson's
○ Care partner or family member



Medication Challenges in the Hospital

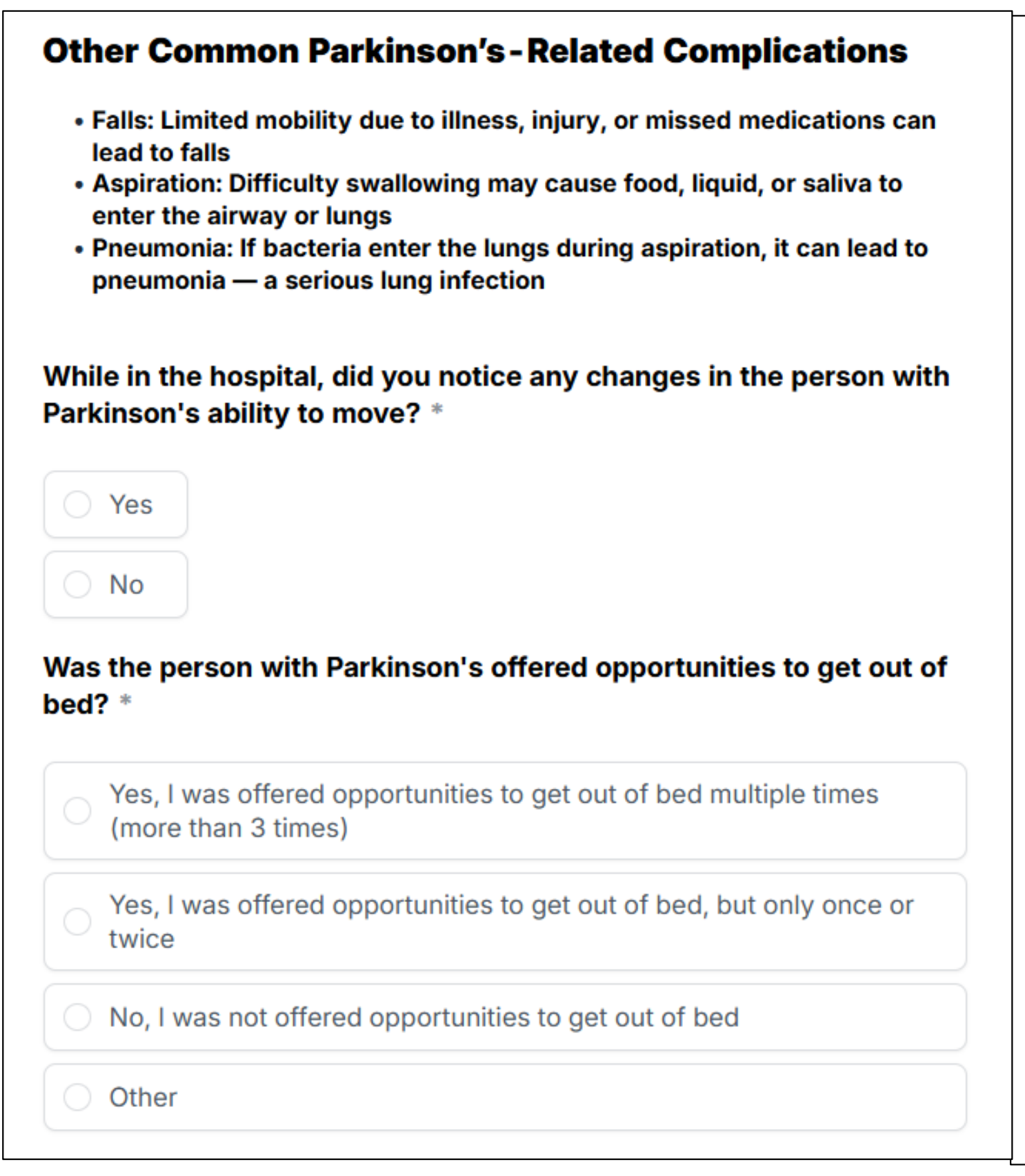
Having a record of any medication issues during you or a loved one's hospital stay can help prepare for future hospital visits or Parkinson's appointments.

During the hospital stay, did the person with Parkinson's experience any of these medication issues? Select all that apply *

☐ I did not receive the exact Parkinson's medications I take at home (they were substituted)
☐ I missed multiple doses of my Parkinson's medications
☐ My medications were given more than an hour off from my usual schedule, more than once
☐ I received medications that made my Parkinson's symptoms worse
☐ I did not experience any medication errors
☐ Other

Did you discuss the person with Parkinson's needs with anyone on the medical team? *

○ Yes
○ No



Other Common Parkinson's-Related Complications

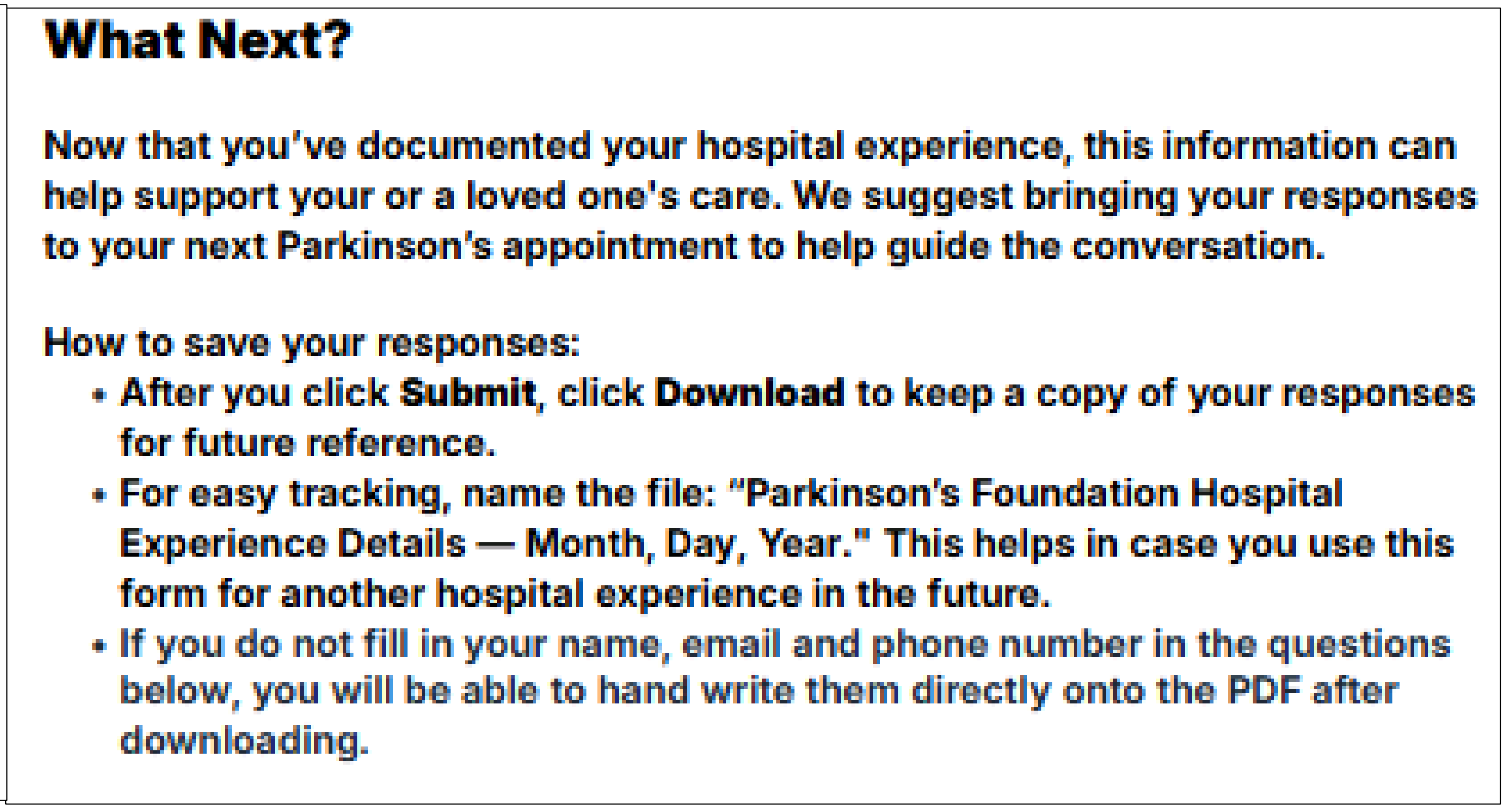
- Falls: Limited mobility due to illness, injury, or missed medications can lead to falls
- Aspiration: Difficulty swallowing may cause food, liquid, or saliva to enter the airway or lungs
- Pneumonia: If bacteria enter the lungs during aspiration, it can lead to pneumonia — a serious lung infection

While in the hospital, did you notice any changes in the person with Parkinson's ability to move? *

○ Yes
○ No

Was the person with Parkinson's offered opportunities to get out of bed? *

○ Yes, I was offered opportunities to get out of bed multiple times (more than 3 times)
○ Yes, I was offered opportunities to get out of bed, but only once or twice
○ No, I was not offered opportunities to get out of bed
○ Other



What Next?

Now that you've documented your hospital experience, this information can help support your or a loved one's care. We suggest bringing your responses to your next Parkinson's appointment to help guide the conversation.

How to save your responses:

- After you click **Submit**, click **Download** to keep a copy of your responses for future reference.
- For easy tracking, name the file: "Parkinson's Foundation Hospital Experience Details — Month, Day, Year." This helps in case you use this form for another hospital experience in the future.
- If you do not fill in your name, email and phone number in the questions below, you will be able to hand write them directly onto the PDF after downloading.

PD GENEration
POWERED BY THE PARKINSON'S FOUNDATION

LARGE-PD Latin American Research consortium on the GEnetics of Parkinson's Disease

asap Aligning Science Across Parkinson's

gp2 Global Parkinson's Genetics Program

Empowering Hispanic/Latino Communities Through Research and Education: Expanding Access to Parkinson's Genetics Studies Across Latin America

Anny Coral-Zambrano[1], Miguel Inca Martínez[2], Priscila D. Hodges[3], Joshua Ruffner[1], Ignacio Azcarate[1], Nicola Bothwick[1], Kamalini Ghosh Galvelis[1], Megan Dini[1], Allison Dilliott[1], Lark Caboy[1], Margaret Caulfield[1], Melissa Nicewaner[1], Addison Yake[1],
James C. Beck[1], Roy N. Alcalay[4,5,] Ignacio F. Mata[2], Rebeca De León[1], and The Parkinson's Foundation PD GENEration Study.

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Background

Hispanic/Latino individuals remain underrepresented in Parkinson's Disease (PD) genetic research due to various barriers, including limited awareness, language differences, and disparities in healthcare access. To address this gap, in 2024 the PD GENEration (PDGENE) study initiated a strategic collaboration with the Latin American Research Consortium on the GEnetics of Parkinson's Disease (LARGE-PD) for the study expansion across Latin America, offering CLIA-certified genetic testing and counseling at no cost. This initiative aims to enhance diversity in PD research.

Methods

LATAM Site Expansion and Events Timeline

June 2024
- **Centro de Trastornos del Movimiento** (CETRAM) in Chile makes its first enrollment
- **Fundación Valle del Lili** (FVL) in Colombia makes its first enrollment

August 2024
- **Instituto Nacional de Ciencias Neurológicas** in Peru makes its first enrollment

September 2024
INNN and FVL recruitment events

September 2024
- **Instituto Nacional de Neurología y Neurocirugía "Manuel Velasco Suárez"** (INNN) in Mexico makes its first enrollment

November 2024
- **Universidad Andrés Bello** (UNAB) in El Salvador makes its first enrollment

2025

July 2025
UNAB recruitment event

August 2025
- **Universidad Concepción** makes its first enrollment
- **Unión Médica del Norte, Clínica Universitaria** (UMN) in the Dominican Republic makes its first enrollment.
- **Universidad Nacional Autónoma de México** (UNAM) makes its first enrollment

September 2025
- **Clínica Santa María** makes its first enrollment

September 2025
DR recruitment event

2026

January 2026
- **Hospital General de Agudos Ramos Mejía** in Argentina makes its first enrollment
- **Universidad Católica del Norte** (UCN) makes its first enrollment

LATAM Event Patient Workflow (PDGENE / LARGE-PD)

1) Engagement
- Event Registration
- Study Registration

REGISTRATION

2) Education & Consent

CONSENT
- Study Overview
- Consent Review (PDGENE/LARGE-PD)
- Consent signature

3) Clinical Assessment

Neurological evaluation

LARGE-PD/PDGENE surveys completion

4) Sample Collection and Processing
- De-identified sample ID generation
- Sample Collection
- **PDGENE:** Samples are processed by US CLIA-certified lab
- **LARGE-PD:** Samples are shipped to Cleveland Clinic Foundation for research-grade analysis

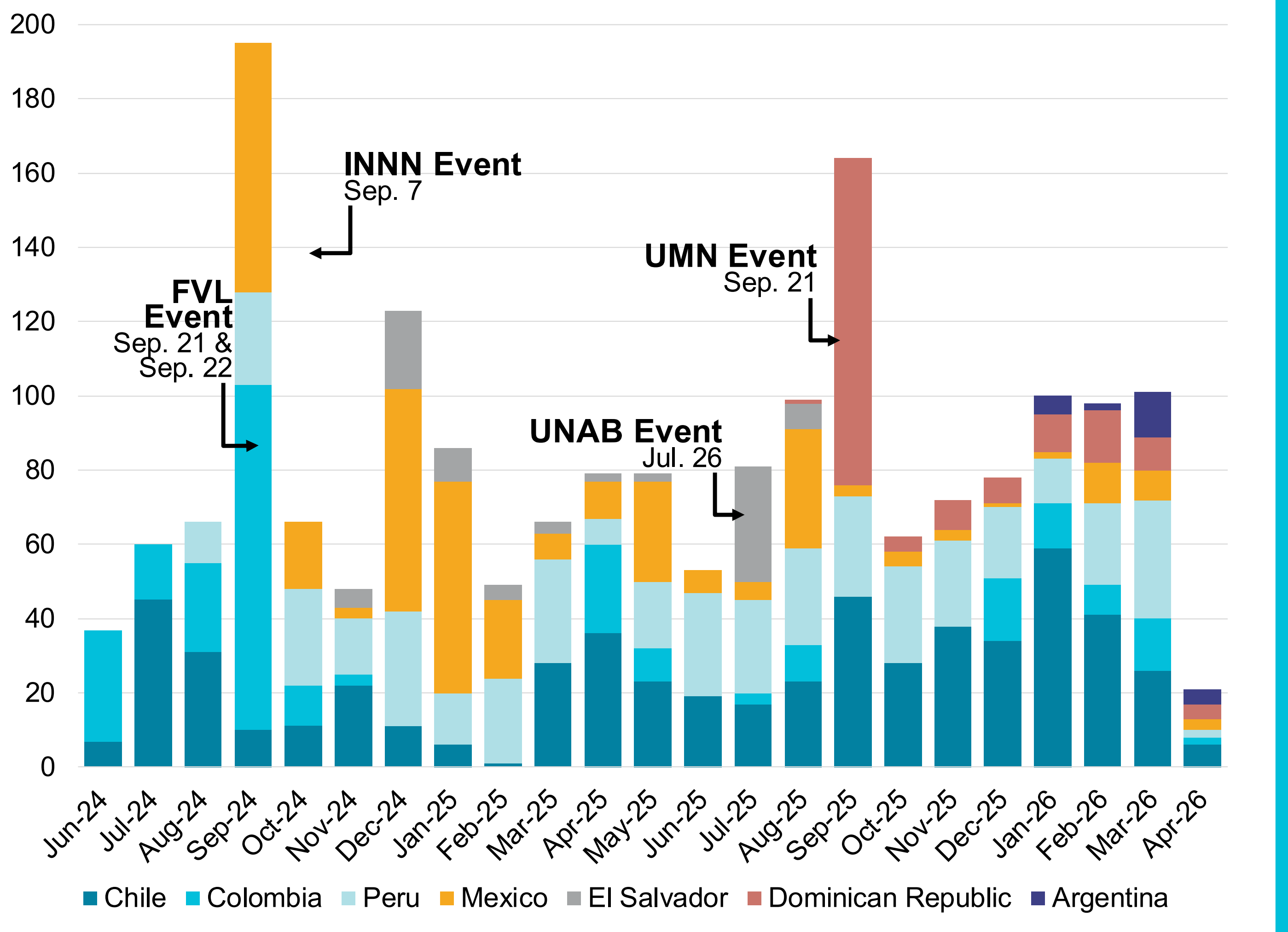
5) Results and Follow Up
- Results are returned by LATAM clinicians trained to provide genetic counseling

Results

Enrollment

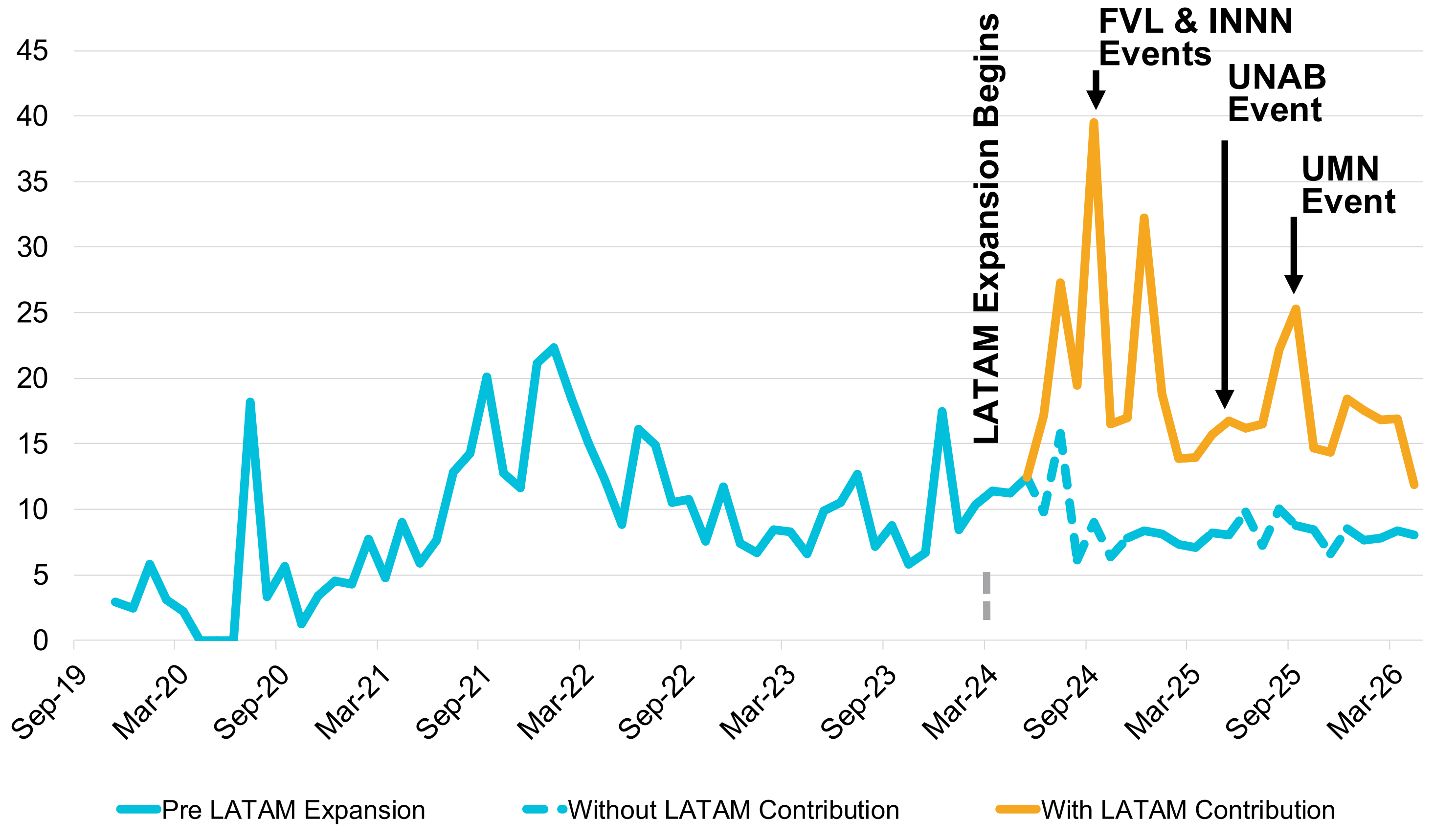
As of April 13th, 2026, PD GENEration has enrolled 1,883 participants in Latin America since the start of LATAM expansion in June of 2024.

These efforts expanded participation among historically underrepresented Hispanic/Latino populations in Parkinson's genetic research. By combining culturally tailored education with direct access to enrollment, this initiative addressed key knowledge gaps and barriers to participation. Increasing diverse representation is critical to improving our understanding of Parkinson's disease and advancing more inclusive and effective future treatments.



Monthly Enrollment by Country
Enrollment in LATAM has been 82 participants per month on average since the start of LATAM expansion. Incorporation of recruitment events led to significant spikes in enrollment, and addition of new sites has increased monthly enrollment averages over time.

Demographics



LATAM Contribution to Hispanic/Latino Enrollments
Expansion into LATAM has significantly increased Hispanic/Latino representation in PDGENE, accounting for an average of 9.7% of the observed increase in enrollment since expansion began.

Outcomes

INNN **Mexico City** **Sep. 2024**	200+ attendees; 85 participants enrolled; first PDGENE event in Mexico with strong community engagement & educational outreach
FVL **Cali** **Sep. 2024**	2-day event; 55 participants enrolled; 150+ attendees engaged in educational and wellness activities
UNAB **San Salvador** **Jul. 2025**	17 participants enrolled; establishment of the first Parkinson's support group in the country
UMN **Santiago** **Sep. 2025**	89 participants enrolled in a single day—the largest PD GENEration event to date

Avances en Parkinson y Genética: Ciencia Que Transforma Vidas
Proyecto PD GENEration LARGE-PD
Santiago de Los Caballeros

APRENDA SOBRE EL PARKINSON
Incluye refrigerio y almuerzo
- Descripción de la Enfermedad
- Ejercicio y nutrición
- Genética de la enfermedad de Parkinson
- Consejería genética para la enfermedad de Parkinson

PARTICIPE EN LA INVESTIGACIÓN
- Estudio libre de costo
- La participación en el estudio toma aproximadamente 45 minutos
- No se requiere ninguna preparación
- Toma de muestra para prueba genética de Parkinson

Día: Domingo 21 de septiembre de 2025
Lugar: Centro de Convenciones y Cultura Dominicana UTESA
Ave. Las Carreras, esq. Ave. Francia
Santiago de Los Caballeros, República Dominicana
(Frente al Monumento)
Hora: 8:00 a.m. - 3:00 p.m

Para registrarse
Llame al (809) 982-9247
O escaneé el código QR

LATAM Recruitment Events with LARGE-PD
LATAM-specific recruitment events reached ~700 individuals and resulted in 240 new enrollments across four Latin American countries.

Conclusion

Research and genetics educational events, along with culturally adapted recruitment strategies, help reduce barriers, raise awareness, and boost Hispanic/Latino participation in PD genetic research. Collaboration with clinicians and community leaders builds trust and enhances recruitment. Sustained, community-driven efforts are key to addressing disparities, and future initiatives should focus on ongoing engagement and expanded partnerships to improve representation in PD research.

Resources

Learn more about PD GENEration and our current findings

Joining Forces: A Collaborative Partnership between the Veterans Health Administration and the Parkinson's Foundation

Emily Hall, LCSW[1], Gretchen Glenn, LCSW[1], Emily Buetow, MSW[2], Jessica Kaplan, RN[1],
Annie Li Wong, MS, RN GNP[1], Hannah Wetherholt[2], Sheera Rosenfeld[2], Dawn McHale[1] & John Duda, MD[1]

Introduction

There are more than 110,000 Veterans living with Parkinson's disease (PD) in the United States. For some veterans, developing PD may be associated with exposure to Agent Orange and other herbicides during military service.

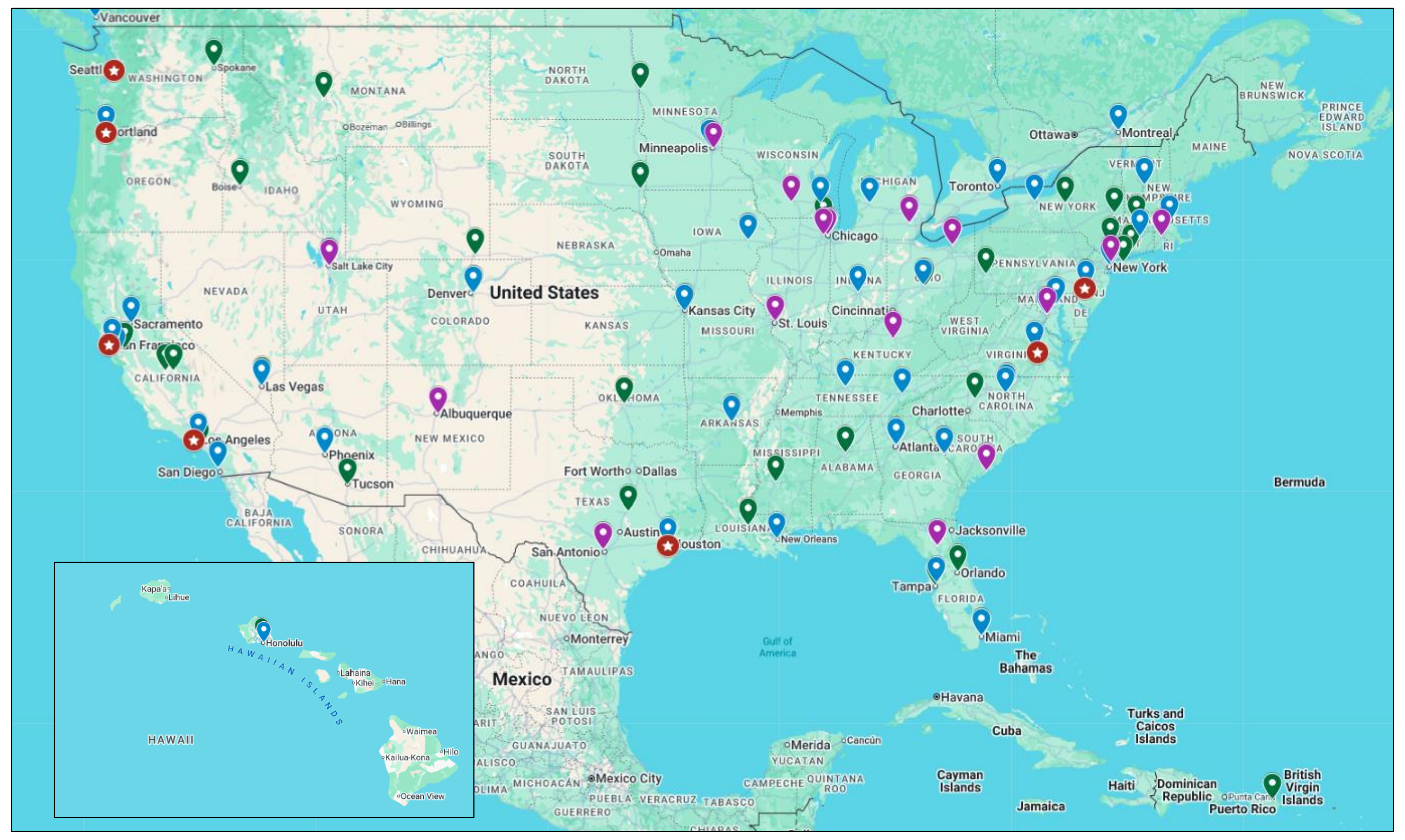
In 2001, the Veteran's Health Administration (VHA), within the Department of Veterans Affairs (VA), established the Parkinson's Disease Research, Education & Clinical Centers (PADRECCs) to provide comprehensive PD care. The PADRECC Network comprises six PADRECCs, 16 Regional Parkinson's and Movement Disorder Centers, and 40 PADRECC Associated Sites. In April 2020, the Parkinson's Foundation (PF) entered into a formal partnership with the VHA with the goal of improving the health, well-being and quality of life of Veterans living with PD.

Methodology

Through their partnership, the VA and the Parkinson's Foundation focus on making it easier for Veterans with PD and their loves ones to locate resources and care through a unique portfolio of co-created resources. Highlighted partnership projects include the development and distribution of Veteran-specific educational resources and webinars, PD-specific training opportunities for VA clinicians provided through PF, and VA-led training for the Parkinson's Foundation Helpline and Chapter teams on supporting Veterans with PD and their care partners.

PADRECC and Parkinson's Foundation leadership meet biweekly to discuss, plan, and execute partnership goals, with larger meetings between the PADRECC Network and Parkinson's Foundation team held every other month to provide programmatic updates and discuss future collaborations.

Parkinson's Foundation & National VA PD Network



● VA PADRECCs
● VA PADRECC Associated Sites
● VA Regional Parkinson's & Movement Disorder Centers
● PF Global Care Network Centers

Results

Since the partnership launched in 2020, the VA and the Parkinson's Foundation have expanded reach to better serve Veterans with PD, care partners, and VA professionals.

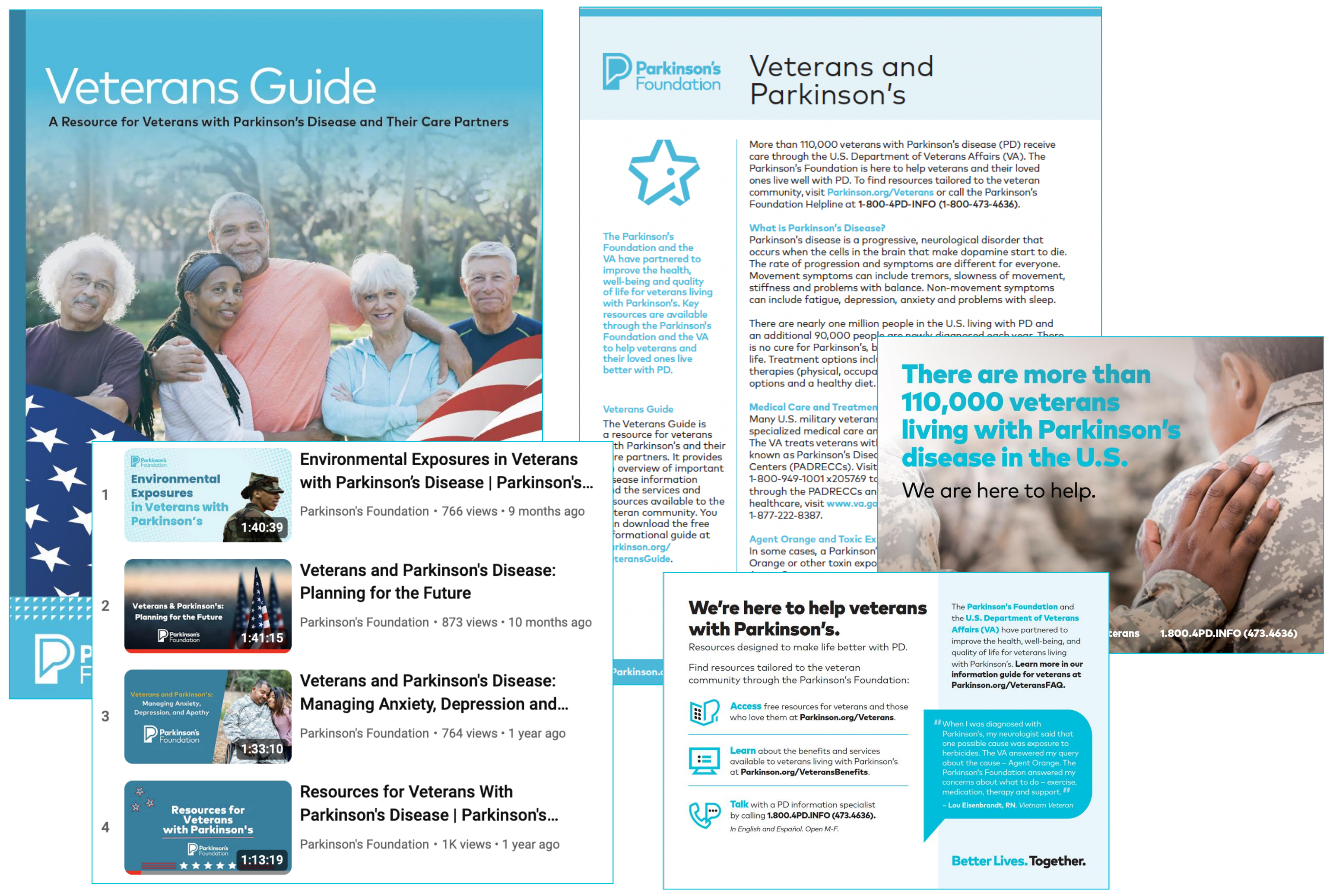
20,000+ Veterans with PD and loved ones reached
by registering for a Parkinson's Foundation event, requesting resources from the Parkinson's Foundation, participating in the the PD GENEration global study, or contacting the Parkinson's Foundation Helpline.

20+ webinars for Veterans with 16,000+ registrations
with VA professionals and Veteran community members engaged in every step of the process from topic selection to expert speaking roles. Topics have included accessing VA resources, the role of care partners, navigating advancing needs, mental wellness, and many more.

6 co-created educational print and digital resources
including dedicated Veteran webpages on Parkinson.org, collaboratively developed by the VA and the Parkinson's Foundation and updated annually to provide accurate and clear information to Veterans, their loved ones, and VA professionals.

150+ VA professionals participating in PF Team Training
with scholarships provided through the Parkinson's Foundation to support increased knowledge, communication, and collaboration among healthcare professionals working in the PD community.

Partnership Impact Spotlight: 12,500+ PF Helpline Cases Related to Veterans
The VA and Parkinson's Foundation partnership enables the Parkinson's Foundation Helpline team to connect directly with PADRECC staff about questions from individual Helpline users. This close collaboration has helped ensure that Veterans with PD receive access to specialized care and support.



Veterans Guide
A Resource for Veterans with Parkinson's Disease and Their Care Partners

Parkinson's Foundation
Veterans and Parkinson's

More than 110,000 veterans with Parkinson's disease (PD) receive care through the U.S. Department of Veterans Affairs (VA). The Parkinson's Foundation is here to help veterans and their loved ones live well with PD. To find resources tailored to the veteran community, visit Parkinson.org/Veterans or call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (1-800-473-4636).

What is Parkinson's Disease?
Parkinson's disease is a progressive, neurological disorder that occurs when the cells in the brain that make dopamine start to die. The rate of progression and symptoms are different for everyone. Movement symptoms can include tremors, slowness of movement, stiffness and problems with balance. Non-movement symptoms can include fatigue, depression, anxiety and problems with sleep.

The Parkinson's Foundation and the VA have partnered to improve the health, well-being and quality of life for veterans living with Parkinson's. Key resources are available through the Parkinson's Foundation and the VA to help veterans and their loved ones live better with PD.

Veterans Guide

Medical Care and Treatment

Agent Orange and Toxic Exposures

1. Environmental Exposures in Veterans with Parkinson's Disease | Parkinson's…
Parkinson's Foundation • 766 views • 9 months ago
1:40:39

2. Veterans and Parkinson's Disease: Planning for the Future
Parkinson's Foundation • 873 views • 10 months ago
1:41:15

3. Veterans and Parkinson's Disease: Managing Anxiety, Depression and…
Parkinson's Foundation • 764 views • 1 year ago
1:33:10

4. Resources for Veterans With Parkinson's Disease | Parkinson's…
Parkinson's Foundation • 1K views • 1 year ago
1:13:19

There are more than 110,000 veterans living with Parkinson's disease in the U.S.
We are here to help.
1.800.4PD.INFO (473.4636)

We're here to help veterans with Parkinson's.
Resources designed to make life better with PD.
Find resources tailored to the veteran community through the Parkinson's Foundation:

Access free resources for veterans and those who love them at Parkinson.org/Veterans.

Learn about the benefits and services available to veterans living with Parkinson's at Parkinson.org/VeteransBenefits.

Talk with a PD information specialist by calling 1.800.4PD.INFO (473.4636).
In English and Español. Open M-F.

The Parkinson's Foundation and the U.S. Department of Veterans Affairs (VA) have partnered to improve the health, well-being, and quality of life for veterans living with Parkinson's. Learn more in our information guide for veterans at Parkinson.org/VeteransFAQ.

"When I was diagnosed with Parkinson's, my neurologist said that one possible cause was exposure to herbicides. The VA answered my query about the cause – Agent Orange. The Parkinson's Foundation answered my concerns about what to do – exercise, medication, therapy and support."
– Lou Eisenbrandt, RN, Vietnam Veteran

Better Lives. Together.

Scan for more info about the PADRECCs and how to establish care!
Parkinsons.VA.gov

Scan for Veteran information from the Parkinson's Foundation!
Parkinson.org/Veterans

Conclusion

The partnership continues to thrive and evolve, enhancing access to VA care for Veterans with PD. With future projects already under development, the collaboration is poised for continued expansion. This dynamic partnership underscores a steadfast commitment to the health and well-being of our Veterans.

Parkinson's Foundation Helpline
1-800-4PD-INFO (473-4363)
Helpline@Parkinson.org

National VA Network Hotline
1-800-949-1001 x205769

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[1] VA PADRECCs
[2] Parkinson's Foundation

Parkinson's Foundation

Parkinson.org

Parkinson's Exercise Guidelines: From Outdated to Updated

Lisa Hoffman, MA;[1] Lauren Krasucki, PT, DPT, MPH, CPH;[1] Miriam R. Rafferty, DPT, PhD;[2] Daniel M. Corcos, PhD[3]
[1]Parkinson's Foundation, New York, NY; [2]Shirley Ryan AbilityLab, Chicago, IL; [3]Northwestern University, Chicago, IL

Background

- In 2021, the Parkinson's Foundation, in partnership with the American College of Sports Medicine, created new Parkinson's disease (PD) exercise recommendations to ensure that people with Parkinson's are receiving safe and effective exercise programs and instruction.
- Clinical guidelines are generally reviewed and updated every three to five years to ensure that the information remains relevant and contributes to high-quality, evidence-based care.

Objective

- To align the 2021 Parkinson's Foundation Exercise Guidelines with current evidence and stakeholder feedback.

Methodology

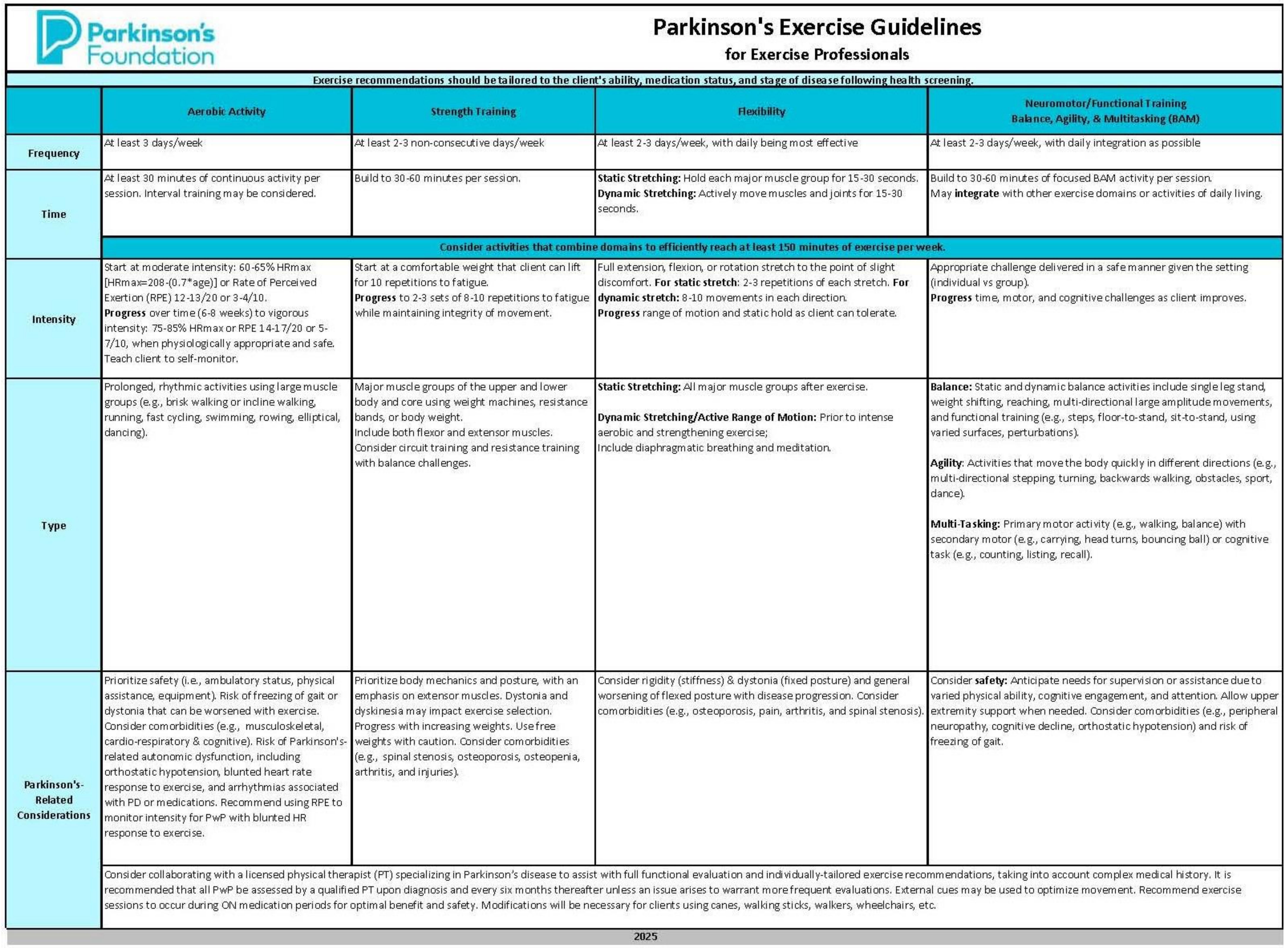
- An internal committee of four subject-matter experts (SMEs) conducted a focused literature search to identify and correct gaps in the recommendations.
- The revised professional-facing guidelines were then examined by a panel of 11 international SMEs and individuals with PD.
- The internal committee refined the guidelines based on the panelists' feedback, after which a public comment period was initiated.
- Eight comments were received during the public comment period, and the internal committee utilized these comments to further improve the guidelines and facilitate resource development.

Results

- SMEs collectively agreed on the importance of safety, referral to a physical therapist, and modifications based on the client's ability, medication status, and stage of disease.
- The BAM domain was expanded to more accurately describe the distinctive aspect of exercise prescription.
- The current literature dictated changes to the time component of strength training, flexibility, and BAM.
- SMEs provided valuable suggestions of PD-related considerations and examples of relevant activities across domains.
- Formatting was improved for clarity and flow, and concepts were widely simplified.

Conclusion

- SMEs achieved consensus aligning the guidelines with current evidence, disseminating this information as a practical, user-friendly guide for exercise professionals who work with people with Parkinson's.



Parkinson's Foundation

Parkinson's Exercise Guidelines

for Exercise Professionals

Exercise recommendations should be tailored to the client's ability, medication status, and stage of disease following health screening.

	Aerobic Activity	Strength Training	Flexibility	Neuromotor/Functional Training Balance, Agility, & Multitasking (BAM)
Frequency	At least 3 days/week	At least 2-3 non-consecutive days/week	At least 2-3 days/week, with daily being most effective	At least 2-3 days/week, with daily integration as possible
Time	At least 30 minutes of continuous activity per session. Interval training may be considered.	Build to 30-60 minutes per session.	**Static Stretching:** Hold each major muscle group for 15-30 seconds. **Dynamic Stretching:** Actively move muscles and joints for 15-30 seconds.	Build to 30-60 minutes of focused BAM activity per session. May **integrate** with other exercise domains or activities of daily living.
	Consider activities that combine domains to efficiently reach at least 150 minutes of exercise per week.			
Intensity	Start at moderate intensity: 60-65% HRmax [HRmax=208-(0.7*age)] or Rate of Perceived Exertion (RPE) 12-13/20 or 3-4/10. **Progress** over time (6-8 weeks) to vigorous intensity: 75-85% HRmax or RPE 14-17/20 or 5-7/10, when physiologically appropriate and safe. Teach client to self-monitor.	Start at a comfortable weight that client can lift for 10 repetitions to fatigue. **Progress** to 2-3 sets of 8-10 repetitions to fatigue while maintaining integrity of movement.	Full extension, flexion, or rotation stretch to the point of slight discomfort. **For static stretch**: 2-3 repetitions of each stretch. **For dynamic stretch:** 8-10 movements in each direction. **Progress** range of motion and static hold as client can tolerate.	Appropriate challenge delivered in a safe manner given the setting (individual vs group). **Progress** time, motor, and cognitive challenges as client improves.
Type	Prolonged, rhythmic activities using large muscle groups (e.g., brisk walking or incline walking, running, fast cycling, swimming, rowing, elliptical, dancing).	Major muscle groups of the upper and lower body and core using weight machines, resistance bands, or body weight. Include both flexor and extensor muscles. Consider circuit training and resistance training with balance challenges.	**Static Stretching:** All major muscle groups after exercise. **Dynamic Stretching/Active Range of Motion:** Prior to intense aerobic and strengthening exercise; Include diaphragmatic breathing and meditation.	**Balance:** Static and dynamic balance activities include single leg stand, weight shifting, reaching, multi-directional large amplitude movements, and functional training (e.g., steps, floor-to-stand, sit-to-stand, using varied surfaces, perturbations). **Agility**: Activities that move the body quickly in different directions (e.g., multi-directional stepping, turning, backwards walking, obstacles, sport, dance). **Multi-Tasking:** Primary motor activity (e.g., walking, balance) with secondary motor (e.g., carrying, head turns, bouncing ball) or cognitive task (e.g., counting, listing, recall).
Parkinson's-Related Considerations	Prioritize safety (i.e., ambulatory status, physical assistance, equipment). Risk of freezing of gait or dystonia that can be worsened with exercise. Consider comorbidities (e.g., musculoskeletal, cardio-respiratory & cognitive). Risk of Parkinson's-related autonomic dysfunction, including orthostatic hypotension, blunted heart rate response to exercise, and arrhythmias associated with PD or medications. Recommend using RPE to monitor intensity for PwP with blunted HR response to exercise.	Prioritize body mechanics and posture, with an emphasis on extensor muscles. Dystonia and dyskinesia may impact exercise selection. Progress with increasing weights. Use free weights with caution. Consider comorbidities (e.g., spinal stenosis, osteoporosis, osteopenia, arthritis, and injuries).	Consider rigidity (stiffness) & dystonia (fixed posture) and general worsening of flexed posture with disease progression. Consider comorbidities (e.g., osteoporosis, pain, arthritis, and spinal stenosis).	Consider **safety:** Anticipate needs for supervision or assistance due to varied physical ability, cognitive engagement, and attention. Allow upper extremity support when needed. Consider comorbidities (e.g., peripheral neuropathy, cognitive decline, orthostatic hypotension) and risk of freezing of gait.
	Consider collaborating with a licensed physical therapist (PT) specializing in Parkinson's disease to assist with full functional evaluation and individually-tailored exercise recommendations, taking into account complex medical history. It is recommended that all PwP be assessed by a qualified PT upon diagnosis and every six months thereafter unless an issue arises to warrant more frequent evaluations. External cues may be used to optimize movement. Recommend exercise sessions to occur during ON medication periods for optimal benefit and safety. Modifications will be necessary for clients using canes, walking sticks, walkers, wheelchairs, etc.			

2025

July 2024
Internal Committee Convening

August - November 2024
Internal Committee Updated Guidelines

January 2025
External Review of Guidelines

February – March 2025
Internal Committee Refined Guidelines

April – June 2025
Public Comment Period

July 2025
Internal Committee Refined Guidelines

September 2025
Guidelines Published

HOPE PALS: The Power of Collaboration at the Service of the Spanish-speaking Parkinson's Community

CLAUDIA MARTINEZ, CAMILA GADALA-MARIA, RUBY VILLALOBOS, CLEMIE PIZZILLO, FRANCISCO DOBLAS, SARA CORREAL, PAMELA HARRIS, IGNACIO F MATA, ROSA PEÑA, ADRIANA JIMENEZ

Objective:

To maximize resources and improve the experience of Spanish-speaking individuals and families affected by Parkinson's through collaboration, awareness building, and knowledge sharing among organizations serving the Hispanic community.

Background:

Before 2023, Parkinson's organizations offering Spanish-language educational materials and programs often worked in isolation, resulting in overlapping events, duplicated resources, and missed opportunities for joint impact. The COVID-19 pandemic dramatically expanded digital engagement among Hispanic Parkinson's communities, connecting individuals across the U.S., Latin America, and Spain and creating new potential—and need—for organizational collaboration.

1. HOPE PALS round table at WPC 2023
2. Conference Together beyond Parkinson's
3. Hispanic Leadership Conference 2023
4. Espacio Parkinson with HOPE PALS April 2026
5. Parkinson Positivos Book reading in Coral Gables, Fl.

Methods:

The Davis Phinney Foundation launched HOPE PALS (Hispanic Organizational Partners Engaged in Parkinson's Awareness and Leadership Solutions) to unite leaders from national and international Parkinson's organizations. Beginning in early 2023, monthly virtual meetings and a shared calendar were established to share events, improve communication and foster partnerships. Coalition members include the American Parkinson's Disease Association, Davis Phinney Foundation, LARGE-PD, The Michael J. Fox Foundation, Muhammad Ali Parkinson Center, Parkinson's Foundation, PMD Alliance, Promotores Embajadores de Parkinson and Power for Parkinson's, later joined by the Federación Española de Parkinson and Fundación Degén in Spain.

1.

Results:

Through regular monthly meetings, organizations have reduced scheduling conflicts, expanded cross-promotion of resources, and inspired new collaborative projects—like Parkinson Positivos, an illustrated educational book created through a partnership among the American Parkinson's Disease Association, Columbia University, and the Davis Phinney Foundation (DPF). Twice-yearly (April and September), the DPF's Espacio Parkinson webinar invites coalition members to showcase materials and events, strengthening visibility and access for the Spanish-speaking Parkinson's community.

Conclusion:

HOPE PALS demonstrates the power of cross-organizational collaboration to amplify education and support for underserved Parkinson's communities. By leveraging digital connections and shared leadership, this coalition has elevated collective impact, enhanced community trust, and expanded culturally relevant resources for the international Spanish-speaking Parkinson's community.

2.

3.

4.

Espacio Parkinson - Mes de la Concientización del Parkinson

5.